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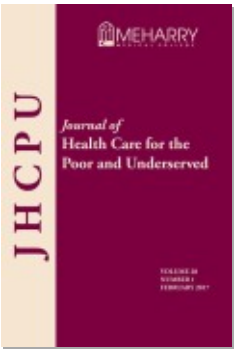

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Perceived Barriers and Facilitators to Health Care Utilization in the United States for Transgender People: A Review of Recent Literature

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Abstract: Transgender people face numerous barriers when utilizing health care in the United States. The current study sought to highlight transgender consumer perspectives in order to present theoretically informed, concrete recommendations for increasing transgender health care utilization. The search yielded several prominent themes associated with barriers to health care for transgender people: 1) provider lack of knowledge concerning transgender identity issues and transgender health issues, 2) transgender patients' previous negative experiences with the health care system or anticipation of these experiences, 3) transgender patients' inability to pay for health care services, and 4) health care provider refusal to provide health care services to transgender people. We present a modified version of Adapted Behavioral Model of health care utilization for transgender people focused on transgender individuals as a guiding theoretical framework that informs our recommendations for increasing transgender health care utilization.

Key words: Transgender; gender nonconforming; health care utilization; health services for transgender people; Behavioral Model of Health Services Use; health care barriers.

Transgender individuals experience high levels of health disparities within the United States when compared with the cisgender (non-transgender) population. Over 50% of transgender people, on average, delay needed medical care compared with about 20% of the cisgender population in the U.S.[1,2] Transgender women in the United States are about six times more likely to experience significant depressive symptoms than the cisgender population.[3] Prevalence and incidence rates of HIV among transgender women are also higher than most other populations in the United States.[4] These transgender patients represent a vulnerable subgroup of health care consumers with individualized health care needs related to their transgender experience.[5]

In order to provide competent medical care to transgender individuals, knowledge development concerning transgender related issues and terminology is critical for medical professionals. Developing cultural competence is one of the major components of the mission of the health and social welfare field.[6] Providing accurate and non-pathologizing

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information about the transgender community can help combat negative stereotypes that providers often associate with this community.[7] Combating these stereotypes can then counter the negative impacts of discrimination and bias that result through direct and indirect service delivery models.[7]

In the past decade, trainings to increase organizational competence concerning transgender issues have emerged as a strategy to address transgender health disparities.[8] These workshops are often called *Transgender 101* trainings and are targeted towards health care professionals.[8] Kenagy has suggested that health care provider trainings on transgender identity and health needs are vitally important.[9] Clinicians who want to affirm transgender people often unknowingly reinforce a gender binary system.[10] The presence of educational content surrounding transgender issues can result in health care providers possessing a stronger desire to work with the transgender population.[7] Professional organizations, such as The American Public Health Association (APHA), have been working to increase provider motivation to serve transgender populations by providing more opportunities to learn about transgender consumer health care needs.[11]

Discrimination faced by transgender people within health care settings has been identified as a central cause of their underutilization of health care.[12] Many transgender people will postpone medical care when sick or injured due to the fear of discrimination.[13] Not only do transgender people (particularly low-income people and people of color) report high levels of discrimination within health care settings, these levels are often higher than other gender and sexual minorities.[14] Furthermore, HIV/AIDS health services (an area traditionally perceived as lesbian, gay, bisexual, and transgender friendly) have also been documented as being insensitive to the health care needs of transgender individuals.[15,16] In order to combat the discrimination transgender people face, health care schools and institutions have attempted to implement structural interventions that will provide health care practitioners the training and skills (such as those mentioned above) to work with this population. Despite these attempts, transgender people continue to underutilize health care.[1]

Most research focusing on transgender health care has simply documented the discrimination that transgender individuals experience when using health care without providing a larger framework for understanding why health care utilization is low for transgender populations. In order to understand the major perceived barriers and facilitators to transgender people utilizing health care in the U.S., the current study examined recent qualitative and quantitative literature. The study focuses on utilization for common problems related to medical care, such as routine medical visits, mental health services, dental services, transition-related services, and HIV/AIDS care. We use Andersen's Emerging Behavioral Model of Health Services Use as our framework for understanding barriers and facilitators to health care utilization among transgender people.[17,18] This framework has been employed extensively to understand factors related to health care utilization among varying populations but has not been specifically used with the transgender population. The model emphasizes that several environment and person-specific attributes influence health care utilization.[19] We discuss three of these characteristics: (1) predisposing characteristics, (2) enabling resources, and (3) clinical need for care.

Predisposing characteristics are demographic factors (such as age and gender) repre-

senting biological needs that may predict a person's likelihood to need to utilize health care services.[20] Beliefs, attitudes, knowledge, and values about health or health services are also predisposing characteristics that may influence utilization.[19] Enabling resources refer to resources that must be present in order for people to utilize care. For example, health care facilities must exist where people live and work, and people must also have the means to make use of those services. These measures can include income, access to health insurance, travel times to obtain health care, a regular source of health care, and wait times to receive health care.[17] Clinical need for care refers to whether or not people will utilize health care based on whether they feel they have a need for care.

Gelberg, Andersen, and Leak[21] expanded Andersen's Health Behavioral Model[17] and the three aforementioned components to focus on vulnerable populations. Although their expanded model was intended specifically for use with homeless populations, we believe that it can also be used with transgender populations due to the widespread marginalization of both groups. We utilize the Behavioral Model for Vulnerable Populations,[21] Andersen's Emerging Behavioral Model of Health Services Use,[17,18,22] as well as adapt Simpson et al.'s Behavioral Model of Health Care Utilization Adapted to Account for GLB (gay, lesbian, and bisexual)-Related Factors among GLB Veterans[19] to help guide the recommendations we have created from this current review of recent literature. We call our model Andersen's Adapted Behavioral Model of Health Care Utilization for Transgender People. After reviewing the literature, we suggest theory-informed recommendations from our model that can improve health care utilization among transgender people.

Methods

Four databases (GoogleScholar, PubMed, PsychInfo, and Cochran) were searched in November 2015 using the following key words: *transgender health care disparities, transgender health care inequities, transgender health care utilization, transgender health care barriers and facilitators, gender minority health care disparities, gender minority health care inequities, gender minority health care utilization, gender minority health care barriers and facilitators, gender queer health care disparities, gender queer health care inequities, gender queer health care utilization, gender queer health care barriers and facilitators, gender nonconforming health care disparities, gender nonconforming health care inequities, gender nonconforming health care utilization, and gender nonconforming health care barriers and facilitators*. These key words reflected the concepts of "health care utilization" and "transgender." The authors cross-referenced the key words used in published papers in order to identify all the key words utilized in the current study.

Figure 1 presents the flow chart for the selection of the included studies. The initial search rendered 1,244 published English-language abstracts. Both researchers screened the abstracts and excluded studies that did not address barriers or facilitators to health care utilization among transgender individuals from the patient perspective. The authors focused on the patient perspective rather than the provider perspective so that recommendations to improve health care utilization for this population will be as patient centered as possible. This procedure resulted in 38 potential studies.

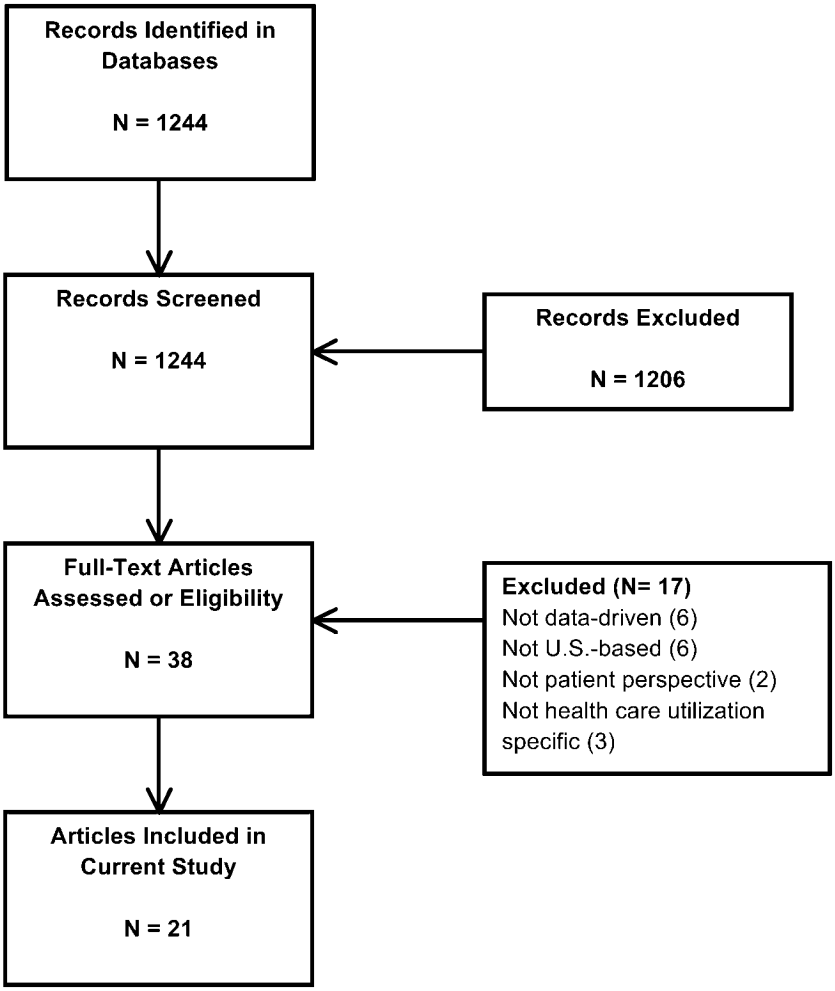

Figure 1. Flow diagram.

The second stage of the study examined each of the 38 studies and excluded all that contained any of the following characteristics:

1. The article was not empirical in nature or data-driven. Conceptual and advocacy articles were excluded.
2. Patients were not explicitly asked about barriers and facilitators to utilizing health care.
3. The study was not conducted in the United States. Health care in the U.S. is largely employer-sponsored. Since no federal employment protections exist for transgender people in the U.S., health care is often tied to employment discrimination. In other high-income countries with universal health care (such as Canada, England, and the Netherlands), health care is not linked to employment discrimination. Accessing health insurance for transgender individuals in the U.S., therefore,

has different implications than for transgender individuals in other high-income countries with universal health care.

4. Study participants were not transgender identified. This criterion was considered as many studies conflated transgender and men who have sex with men (MSM) samples.

Seventeen studies fell into one or more of these characteristics and were excluded from further analyses. This process resulted in a total of 21 studies for inclusion into the review.[9,10,16,23–41]

Each of the studies was coded using a rating sheet that was developed a priori. The sheet contained a list of characteristics including the author, year, research methods employed (qualitative or quantitative), data collection method (e.g., self-administered, interview), sample size, gender (including transgender male, transgender female, genderqueer), age, and ethnicity of participants. Additionally, the researchers coded for clinic-based samples and HIV-focused research. They extracted the barriers and facilitators of each study and used these findings to develop themes.

Each of the 21 studies was examined for specific constructs related to the barriers and facilitators of health care utilization by two researchers. In the event of incongruent results, the researchers discussed the theme in question and agreed on a resolution. The themes in the qualitative and quantitative studies were then extracted. The analyses yielded prominent themes. The researchers assessed the methodological quality of each study utilizing standardized assessments of quality for quantitative and qualitative research, which are discussed in the results section below.

Results

The following section provides an overview of study characteristics including the year and location of the study, the methodologies employed, and the characteristics of the study participants. See Tables 1 and 2 for characteristics for each study for which data were extracted as well as the citations. The authors searched for studies between 2000 and 2015, and the resulting studies were published between 2001 and 2015. Studies before 2000 were excluded since transgender health care is a rapidly expanding field, and the authors wanted to utilize information that would be as relevant and current as possible. All of the studies (n = 21) took place within the United States.

Almost half of the studies were conducted using qualitative methods (n = 9), while the other half of the studies (n = 10) were quantitative with the exception of two mixed methods study. All 10 quantitative studies used a survey method to collect data. Six of the quantitative studies utilized self-administered surveys, three of the studies employed a face-to-face survey, and one study used both methods. The methodology, however, employed in the nine qualitative studies varied: six involved in-depth interviews, two used focus groups, and one employed both focus groups and interviews. Both of the mixed methods studies used self-administered surveys, while one of the studies also used focus groups.

The number of participants in the studies varied widely (from five to 4,049). The qualitative studies employed between five and 58 participants. Sample sizes for the

Table 1.

LIST OF QUALITATIVE STUDIES

Citation	Method	Data Collection Method	Sampling Strategy	Sample Size	Ethnicity	Age Range	Settings	Barrier Themes Extracted	Facilitator Themes Extracted
Benson, 2013	Qualitative	In-depth interviews	Non-probability (Purposive and snowball)	7	86% White	24–57	Community Based Sample	Provider lack of knowledge of transgender issues Inability to pay for health care services/ insurance coverage Provider stigma	Not reported
Corliss et al., 2007	Qualitative	In-depth interviews	Non-probability (Convenience)	18	11% White	16–24	Clinic Based Sample	Provider lack of knowledge of transgender issues Counseling services for transgender patients Therapists as gatekeepers for health services	Integrating health and social services
Hussey, 2006	Qualitative	In-depth interviews	Non-probability (Convenience)	5	80% White	33–58	Community Based Sample	Previous negative experiences with health care system/providers as well as anticipation of these experiences Provider lack of knowledge of transgender issues Discrepancy between names and gender identity on legal documents Coming out to a provider/insurance company	Ability to work as a peer educator Being referred to a provider by a peer
Poteat et al., 2013	Qualitative	In-depth interviews	Non-probability (Purposive)	55	33% White	21–66	Community Based Sample	Provider lack of knowledge of transgender issues Previous negative experiences with health care system/providers as well as anticipation of these experiences Perceived provider attitude towards transgender identity and transgender specific health care Belief that provider cannot meet transgender health needs	Not reported
Roller et al., 2015	Qualitative	Semi-structured, in-depth interviews	Non-probability (Purposive)	25	80% White	21–64	Community Based Sample	Discrimination by healthcare systems Lack of trans-knowledge Hostility by providers Lack of health insurance	Fatalism, accepting that navigating the healthcare system is difficult

(*Continued on p. 133*)

Table 1. (*continued*)

Citation	Method	Data Collection Method	Sampling Strategy	Sample Size	Ethnicity	Age Range	Settings	Barrier Themes Extracted	Facilitator Themes Extracted
Sevelius et al., 2014	Qualitative	Focus Groups and in-depth interviews	Non-probability (Snowball and Street intercept)	58	7% White	20–69	Community Based Sample	Previous negative experiences with health care system/providers as well as anticipation of these experiences	Integrating health and social services
Sperber et al., 2005	Qualitative	Focus Groups	Non-probability (Convenience)	34	52.7%White	16–26, Mean 37	Community Based Sample	Discrepancy between names and gender identity Denial of services	Integrating health and social services/ referral system
Wilson et al., 2013	Qualitative	In-depth interviews	Non-probability (Referral)	10	100% Black	28–55	Community Based Sample	Provider lack of knowledge of transgender issues Provider gender identity stigma Peer distrust in clinic settings	Integrating social support in health care
Xavier et al., 2013	Qualitative	Focus Groups	Non-probability (Convenience)	47	38.3% White	18 or older	Community Based Sample	Provider lack of knowledge of transgender issues Previous negative experiences with health care system/providers as well as anticipation of these experiences Inability to pay for health care services/ insurance coverage Provider gender identity stigma Discrepancy between names and gender identity on legal documents Coming out to a provider/insurance company	Not reported

Table 2.

LIST OF QUANTITATIVE STUDIES

Citation	Method	Data Collection Method	Sampling Strategy	Sample Size	Ethnicity	Age Range	Settings	Barrier Themes Extracted	Facilitator Themes Extracted
Bockting et al., 2004	Quantitative	Self-Administered	Non-probability (Purposive and snowball)	180	Not reported	35–42	Clinic Based Sample	Provider lack of knowledge of transgender issues	Building trust with a provider
Bradford et al., 2013	Quantitative	Self-Administered	Non-probability (Purposive)	350	62% White	37 (Mean)	Community Based Sample	Previous negative experiences with health care system/providers as well as anticipation of these experiences Difficulty obtaining preventive care Inability to pay for health care services/ insurance coverage	Not reported
Cruz, 2014	Quantitative	Self-Administered	Non-probability (Convenience)	4049	79.2% White	36.5 (Mean)	National Transgender Discrimination Survey	Previous negative experiences with health care system/providers as well as anticipation of these experiences Inability to pay for health care services/ insurance coverage	Not reported
Kenagy & Bostwick, 2005	Quantitative	Face-to-Face	Non-probability (Snowball)	111	54.1% POC, 45.9% White	19–70	Community Based Sample	Difficulty obtaining preventive care Denial of services Inability to pay for health care services/ insurance coverage	Not reported
Kenagy, 2005	Quantitative	Face-to-Face & Self-Administered	Non-probability (Snowball)	182	33% White	17–68	Transgender-focused Community Based Organization	Provider lack of knowledge of transgender issues Inability to pay for health care services/ insurance coverage Denial of services	Not reported
Konsenko et al. 2013	Mixed Methods	Self-Administered	Non-probability (Internet convenience)	152	Not reported	18–74	Transgender-focused Community Based Organization	Provider lack of knowledge of transgender identity issues Provider displays of discomfort Denial of services	Not reported

(*Continued on p. 135*)

Table 2. (*continued*)

Citation	Method	Data Collection Method	Sampling Strategy	Sample Size	Ethnicity	Age Range	Settings	Barrier Themes Extracted	Facilitator Themes Extracted
Radix et al., 2014	Mixed Methods	Self-Administered and Focus Groups	Non-probability (Purposive)	50	37% Black, 25.6% Latino/a	18–64	Community Based Sample	Difficulty obtaining preventive care Provider lack of knowledge of transgender identity issues	Provider knowledge of transgender identity issues
Sanchez et al., 2009	Quantitative	Face-to-Face	Non-probability (Convenience)	101	20% White	37 (Mean)	Clinic Based Sample	Provider lack of knowledge of transgender issues Inability to pay for health care services/ insurance coverage	Not reported
Shipherd et al. 2010	Quantitative	Self-Administered	Non-probability (Convenience)	130	92% White	22–79	Transgender-focused Conference	Inability to pay for health care services/ insurance coverage Previous negative experiences with health care system/providers as well as anticipation of these experiences Not wanting to disclose personal issues	Not reported
Shires & Jaffee, 2015	Quantitative	Focus Groups	Non-probability (Convenience)	1711	73.9% White	25–44 (64.2% of sample)	National Transgender Discrimination Survey	Previous negative experiences with health care system/providers as well as anticipation of these experiences Denial of services	Not reported
Stotzer et al., 2014	Quantitative	Self-Administered	Non-probability (Convenience)	710 (170 non-cisgender participants in the sample)	53.4% White	18–83	Community Based Sample	Previous negative experiences with health care system/providers as well as anticipation of these experiences Inability to pay for health care services/ insurance coverage	Not reported
Tanner et al., 2014	Quantitative	Face-to-Face	Non-probability (Community based participatory research)	180 (33 transgendered participants in the sample)	100% Latino	18–61	Community Based Sample	Previous negative experiences with health care system/providers as well as anticipation of these experiences Difficulty obtaining preventive care	Not reported

quantitative studies ranged from 101 to 4,049. Data reported on the age of participants also greatly varied. Most studies provided an age range in years (16 to 83) whereas three studies provided the mean age of participants (37 years). One study, however, reported that participants were 18 or older. All 21 studies included individuals who identified as transgender. Three studies focused exclusively on transgender female individuals. The majority of the studies sampled transgender individuals of various gender identities (including androgyny, gender queer, transgender men, transsexual).

Most of the studies included community-based samples (n = 13). Some of the studies were conducted in a clinic based setting (n = 3). Two studies took place in local community centers. Two of the studies utilized the National Transgender Discrimination Survey data set.[1,38] The majority of the studies involved urban populations. Most studies (n = 12) were conducted with samples irrespective of participant health status. Two studies, however, focused exclusively on HIV-positive individuals.

The quantitative studies did not generally allow participants to identify barriers in a narrative form, with the exception of the mixed methods studies. Participants were asked to rate pre-identified barriers using self-reported Likert-type scales. The quantitative studies focused exclusively on barrier themes, with the exception of one study. The nine qualitative studies identified both perceived barriers and facilitators to health care utilization, commonly employing narratives from participants' experiences. None of the qualitative studies, however, exclusively focused on the perceived facilitators to health care utilization. Barrier and facilitator themes did not differ by geographic location, although the majority of the studies took place in a large U.S. city (n = 10). Some studies used samples from across the U.S. (n = 4) in addition to statewide samples (n = 5). Other studies did not disclose geographic information (n = 2). The barrier and facilitator themes that emerged were consistent and did not differ based on year of publication or year of data collection. Most of the studies (n = 13) included a majority of participants identifying as transgender women, yet many studies (n = 13) also contained significant numbers of transgender men. Few studies exclusively included only transgender women (n = 3) or transgender men (n = 1). Some studies did not provide gender identity categories (n = 2). Findings did not differ based on these varying gender identity groupings.

In order to evaluate the strengths and weaknesses of the quantitative studies, the Methodological Quality Scoring (MQS) system was used. This assessment tool has been previously used and validated in the health literature.[42–45] Scores on the MQS range from 0–20 and contain 11 methodological criteria. Both authors independently scored each study, resulting in a 77% consistent agreement rate for the methodological items across all studies. After the initial coding, the raters met to resolve any disagreement. Frequency distributions for each criterion are presented in Table 3. Methodological Quality Scoring guidelines classify scores as low (0–6), medium (7–14), and high (15–20). Total MQS scores in the present study ranged from 6 to 10. Following the classification guidelines, studies were classified as low (n = 2) and medium quality (n = 10). Both quantitative (n = 10) and mixed methods studies (n = 2) were evaluated using the MQS. See Table 4 for a summary of scores for each study.

The Consolidated criteria for reporting qualitative research (COREQ) is a 32-item checklist used for comprehensive reporting of qualitative studies that utilize in-depth

Table 3.

CRITERIA FOR ASSESSING METHODOLOGICAL QUALITY AND FREQUENCY DISTRIBUTIONS FOR EACH QUALITY CHARACTERISTIC

Methodological Characteristic	Scoring Options[a] (Maximum Total Score = 20 Points)	Distribution of Characteristics Among Articles Frequency, n (%)
Definition of utilization	Not reported: 0	10 (83.3)
	Global: 1	2 (16.7)
	Facet-specific: 2	0 (0)
Validity data for utilization variable scores	Not reported: 0	12 (100)
	Reported: 1	0 (0)
Reliability data for utilization variable scores	Not reported: 0	12 (100)
	Reported: 1	0 (0)
Validity/reliability data for other variables in study	Not reported: 0	10 (83.3)
	Reported: 1	2 (16.7)
Theoretical framework presented	Did not present: 0	11 (91.7)
	Presented: 1	1 (8.3)
Research paradigm	Quantitative: 1	10 (83.3)
	Mixed methods: 2	2 (16.7)
Study design	Correlational or cross sectional: 1	12 (100)
	Longitudinal: 2	0 (0)
Sample Size	Undetermined: 0	0 (0)
	<100: 1	2 (16.7)
	>100 to <300: 2	6 (50)
	>300: 3	4 (33.3)
Sample design	Convenience/nonprobability: 0	11 (91.7)
	Random/probability but not nationally representative: 1	1 (0)
	Random/probability and nationally representative: 2	0 (0)
Data analysis	Quantitative/univariate/descriptive: 1	4 (33.3)
	Bivariate/ANOVA: 2	4 (33.3)
	Multiple/logistic regression: 3	3 (25)
	Multivariate: 4	1 (8.3)
Appropriate inferences of causality	Inappropriate: 0	0 (0)
	Appropriate: 1	12 (100)

[a]Scoring options reflect how many points were allocated for each criteria and were summed to calculate a total MQS score for each study.

Table 4.

METHODOLOGICAL QUALITY SCORE FOR EACH STUDY

Study	A	B	C	D	E	F	G	H	I	J	K	MSQ Score
Bockting et al, 2004	0	0	0	0	0	1	1	2	1	2	1	8
Bradford et al, 2013	0	0	0	0	0	1	1	3	0	4	1	10
Cruz, 2014	1	0	0	0	0	1	1	3	0	3	1	10
Kenagy & Bostwick, 2005	0	0	0	0	0	1	1	2	0	2	1	7
Kenagy, 2005	0	0	0	0	0	1	1	2	0	1	1	6
Kosenko et al, 2013	0	0	0	0	0	2	1	2	0	1	1	7
Radix et al, 2014	0	0	0	0	0	2	1	1	0	1	1	6
Sanchez et al, 2009	0	0	0	0	0	1	1	2	0	2	1	7
Shipherd et al, 2010	1	0	0	1	0	1	1	2	0	1	1	8
Shires & Jaffee, 2015	0	0	0	0	1	1	1	3	0	3	1	10
Stotzer et al, 2014	0	0	0	0	0	1	1	3	0	2	1	8
Tanner et al, 2014	0	0	0	1	0	1	1	1	0	3	1	8

Notes: A: definition of utilization; B: validity data for utilization measures; C: reliability data for utilization measures; D: validity and reliability data for other variables; E: theoretical framework; F: research paradigm; G: study design; H: sample size; I: sample design; J: data analysis; K: appropriate inferences of causality.

interviews and focus groups.[46] The COREQ focuses on three main domains of qualitative research, including research team and reflexivity, study design, and analysis and findings. The authors used this checklist to assess the strengths and weaknesses of the qualitative studies. All qualitative studies (n = 9) and both mixed method studies were included in the checklist. Both authors independently evaluated each study and assigned a value of "1" if the item was addressed in the study and a "0" if the item was not addressed in the study. Scores on the COREQ checklist ranged from 15–27. See Table 5 for the assessment of COREQ items in these studies. While no specific criteria have been used to assign quality to studies when using COREQ, the authors divided the studies into low levels of reporting COREQ criteria (scores ranging from 0–11), medium levels of reporting COREQ criteria (12–23), and high levels of reporting COREQ criteria (24–32). The majority of studies fell into the medium level (n = 10), while one study was rated as high. No studies were categorized within the low level of reporting COREQ criteria.

Prominent barrier themes. *Provider lack of knowledge of transgender identity issues.* Provider lack of knowledge about transgender identity issues emerged as a major barrier to transgender people utilizing health care. The literature emphasizes the importance of having knowledgeable practitioners providing comprehensive care for transgender patients.[28,47] Patients consistently report that providers lack the knowledge necessary to address routine health care needs of transgender people, such as hormone therapy, gynecological services, and HIV prevention counseling.[30] A sample of transgender

Table 5.

CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE RESEARCH (COREQ) CHECKLIST RESULTS

	Benson, 2013	Corliss et al., 2007	Hussey, 2006	Kosenko et al., 2005	Poteat et al., 2013	Radix et al., 2014	Roller et al., 2015	Sevelius et al., 2014	Sperber et al., 2005	Wilson et al., 2013	Xavier et al., 2013
Domain 1: Research team and reflexivity											
Personal characteristics											
1. Interviewer/facilitator	1	1	1	0	1	1	1	0	1	1	1
2. Credentials	1	1	1	1	1	1	1	0	1	1	1
3. Occupation	1	0	1	0	1	1	1	0	1	1	0
4. Gender	1	0	0	0	1	0	0	1	1	0	1
5. Experience and training	0	0	1	0	1	1	0	1	1	1	0
Relationship with participants											
6. Relationship established	0	0	0	0	1	1	0	0	1	0	0
7. Participant knowledge of the interviewer	1	0	0	0	1	0	0	0	1	0	0
8. Interviewer characteristics	1	0	0	0	1	0	0	0	1	0	1
Domain 2: Study design											
Theoretical framework											
9. Methodological orientation and theory	1	0	1	0	1	0	1	1	0	0	1
Participant selection											
10. Sampling	1	1	1	1	1	1	1	1	0	1	1
11. Method of approach	1	1	1	1	1	1	1	1	1	1	0
12. Sample size	1	1	1	1	1	1	1	1	1	1	1
13. Non-participation	0	0	0	0	0	0	0	0	1	0	0
14. Setting of data collection	1	1	0	1	1	0	1	0	0	1	0
15. Presence of non-participants	0	0	0	0	0	0	0	0	0	0	0

(*Continued on p. 140*)

Table 5. (*continued*)

	Benson, 2013	Corliss et al., 2007	Hussey, 2006	Kosenko et al., 2005	Poteat et al., 2013	Radix et al., 2014	Roller et al., 2015	Sevelius et al., 2014	Sperber et al., 2005	Wilson et al., 2013	Xavier et al., 2013
16. Description of sample	1	1	1	1	1	1	1	1	1	1	1
17. Interview guide	0	0	0	1	0	0	0	1	0	0	0
18. Repeat interviews	0	0	0	0	0	0	0	0	0	0	0
19. Audio/visual recording	1	1	1	0	1	0	1	1	0	1	1
20. Field notes	1	1	0	0	1	0	1	0	0	1	1
21. Duration	1	1	0	0	1	1	0	1	0	1	0
22. Data saturation	0	0	0	1	1	0	1	0	0	0	0
23. Transcripts returned	1	0	0	0	0	0	0	0	0	0	0
Domain 3: Analysis and findings											
Data analysis											
24. Number of data coders	1	1	0	1	1	0	1	1	0	0	1
25. Description of the coding tree	1	0	0	1	1	0	1	0	0	1	1
26. Derivation of themes	0	1	1	1	1	1	1	1	0	1	1
27. Software	0	1	0	0	1	0	0	1	0	1	1
28. Participant checking	1	0	1	0	1	0	1	0	0	0	0
Reporting											
29. Quotations presented	1	1	1	1	1	1	1	1	1	1	1
30. Data and findings consistent	1	1	1	1	1	1	1	1	1	1	1
31. Clarity of major themes	1	1	1	1	1	1	1	1	1	1	1
32. Clarity of minor themes	1	1	1	1	1	1	1	1	1	1	1
Total Number of Items Present	23	17	16	15	27	15	20	17	16	19	18

youth ages 16–24 in a youth health clinic identified that a lack of knowledge concerning potentially available services for transgender people coupled with inexperienced physicians often served as a barrier to utilizing transgender-specific services, especially hormone treatment.[28]

Transgender health care consumers commonly believed that health care providers have little if any training regarding transgender issues.[26] This lack of knowledge consistently leads to transgender clients feeling that they have to educate their providers about their health care needs.[25] One study indicated that transgender men identified that a lack of provider knowledge concerning gynecological needs poses a barrier that results in obtaining less than comprehensive care.[25] For example, a provider may not be aware that a transgender man would need a routine Pap smear test based on his medical history. For transgender clients living with HIV, the risk of exacerbating the effects of drug interactions between hormones and HIV medications becomes greater due to a paucity of provider knowledge regarding transgender health concerns.[31] A quantitative study with 101 transgender men from three community health centers in New York City found 32% of the study reporting that trying to find a provider knowledgeable about transgender health issues was the biggest barrier to care these individuals experienced in their lives.[24]

While provider knowledge around transgender identity issues was overwhelmingly related to health-specific concerns, additional concerns related to pronoun use and a general understanding of transgender identity among providers also emerged as important themes. Health care providers are often unknowledgeable about how to navigate transgender identity, especially the appropriate use of pronouns[23,25,30,32,33] as well as patients' needs to use specific male or female names when engaging in phone calls with third parties.[32] Transgender individuals found that pronoun use was not consistent among providers in the same practice; sometimes doctors would use male pronouns while others would use female pronouns for the same client.[27] Patients also believed that using appropriate language and pronouns demonstrated provider competence and conveyed to the patient that the provider was treating the client with dignity and respect.[25] Participants in one study thought that providers should possess some general working knowledge concerning gender identity before working with clients.[30] Other participants often found that providers had limited knowledge about transgender identity and felt as though they had to educate providers regarding their gender identities.[27] When patients believed providers were knowledgeable about transgender identity, they also deemed the providers to be helpful.[28]

Previous negative experiences with the health care system/providers as well as anticipation of these experiences. Previous negative experiences with health care providers have been shown to lead to avoidance of the utilization of the health care system among transgender people.[9,30,31] A study of African American transgender women reported negative experiences utilizing HIV care and support services in which the women were not treated as partners in their care, were received coldly, and were given inaccurate information about their health care, leading to a decrease in motivation to utilize these services.[29] Past negative experiences with providers created an expectation among transgender health care consumers that providers would not listen to their concerns.[30] One study reported experiences with psychotherapists believing that being transgender

is a mental illness.[31] Another study with 4,049 participants reported that 25% of transgender patients postponed seeking curative care when sick due to the anticipation of being discriminated against when going to see a health care provider.[1] Among a highly educated, fully employed, and highly functional transgender sample that would be expected to possess the financial means to utilize health care services, previous negative experiences with health care providers was a major barrier to health care seeking even during times of distress.[10] These negative experiences as well as the anticipation of the experiences create limited health care options for transgender health care consumers as they attempt to avoid future discrimination within health care settings.[27]

Inability to pay for health care services and insurance coverage. Being able to afford the cost of health care services, often due to a lack of health insurance coverage, was a recurring theme in the literature. The cost of hormone therapy and surgery can be exorbitant for transgender clients when insurance companies will not pay this expense.[31] In order to help relieve this cost burden, providers sometimes report a hormone imbalance to insurance companies.[30] Other transgender consumers might have to "bend the truth" so that insurance companies will pay for transgender specific care.[37] For example, a transgender male may have to make up a history of breast cancer in his family in order to have his insurance company cover a mastectomy, since the insurance company would pay for preventive care. A lack of income can also make paying for hormones challenging.[31]

In a sample of 130 transgender people recruited from a conference, 42% of the participants identified the cost of mental health care services as the top barrier to using mental health resources.[10] Since transgender consumers identified psychotherapy as cost-prohibitive,[26,31] these health care consumers often turned to drug and alcohol use as a coping mechanism for mental health concerns, such as depression.[31] More than half the study (52%) showed psychological distress but did not utilize care, and one of the major reasons that participants did not seek care was due to cost.[10] Another study that sampled 101 transgender people in Philadelphia indicated that cost was a major barrier in using the following health care services: general medical care (24.8%), prescription medication and hormones (21.8%), gender-related surgery (39.6%), counseling or therapy (32.7%), and dental care (30.7%).[9] Cruz found that 25% of people postponed care when sick due to a lack of affordability.[1] In general, a transgender person's discomfort with navigating the health care system often has the potential to limit the person's desire to utilize care as well as the person's ability to pay for services.[30]

While the majority of the literature did not report data on the socioeconomic status of participants, a few studies did capture this information.[1,34,38,41] These studies reported that approximately 26%-44% of the participants earned less than $20,000 in annual income. The National Transgender Discrimination Survey, which is the largest study to date focused on transgender individuals, reported that transgender people are four times as likely as the general population to live in extreme poverty.[13] Extreme poverty was defined as a household income of less than $10,000 per year.

Denial of services. Being denied transgender specific health care services as well as general health care services due to transgender identity was another prominent barrier to health care utilization. Transgender individuals discussed the difficulty of finding a therapist when recovering from substance abuse, because therapists refused to help cli-

ents cope simultaneously with substance abuse and transgender identity issues.[30] Health care professionals sometimes explicitly refused to provide treatment. In one study, a physician suggested that a transgender client "see a veterinarian" because a medical doctor was a "doctor for people."[30] In addition to being denied treatment, transgender clients often experienced verbal harassment or physical assault within doctors' offices.[38]

In another study with 111 transgender individuals, 38% of respondents reported that being transgender created a problem for them when they went for a physical, 23% said they were refused transgender-related medical care, 14% indicated difficulty getting emergency health care because they were transgender, 12% described being refused routine medical care because of their transgender identity, 9% were refused counseling for transgender related issues, and 3% were refused counseling simply because they were transgender.[9] In a sample comprised of 152 transgender adults, 21% of the sample was denied services, including provider denial of medical treatments (such as hormone treatments), denial of referrals for surgery, and a refusal to meet and to make appointments with transgender patients.[23] In another study with 182 transgender patients in Philadelphia, 26% of patients (out of 154 that provided information) were denied health care services, such as transgender-related care and HIV prevention services.[9]

Many health care agencies possess inclusive organizational policies as well as embrace accreditation mandates focusing on anti-discrimination practice within service delivery.[48] Despite these mechanisms in place to protect transgender people, many professionals have difficulty separating their own personal attitudes and biases from their professional practice.[48] Kenagy found that health care providers denied medical services to approximately 25% of transgender women and transgender men.[9] Similar findings were uncovered in a 2010 Lambda Legal survey (27% of the sample was refused treatment) and within the National Transgender Discrimination Survey (19% of the sample was refused medical services), which is the largest national transgender discrimination survey to date.[13]

Prominent facilitator theme. The movement towards integrated health care has dominated the literature in recent years.[49,50] Research consistently asserts that patients engaged in comprehensive health care systems fare better than patients who rely on referrals and out-of-network providers.[51] In a few studies, transgender clients referenced the importance of receiving integrated health care services in order to better utilize health care services[28,29,33] The lack of integrated health care services for transgender people highlights the disparity in service provision among community health clinics, large health care campuses, and public health/social welfare organizations that serve transgender clients. The current study recommends that integrated health care services will be more effective than the traditional provider-directed care. This form of practice should be considered the standard of care. Future research needs to address this trend.

Discussion

The four barrier themes dominated both the quantitative and qualitative literature with small and large sample sizes. No major differences were uncovered between these two types of methodologies, except when examining facilitators for healthcare utilization. In the quantitative studies, researchers tended to design studies that focused on having

participants report barriers to utilization. In the qualitative studies, semi-structured interviews and focus groups allowed more flexibility in allowing participants to report health care utilization facilitators. If a facilitator was reported, however, it was often unique to the specific qualitative study and did not emerge in multiple studies or within the quantitative studies.

Once the barrier and facilitator themes emerged from conducting the literature review, the authors developed theoretically informed recommendations that may help increase health care utilization among transgender people. These recommendations are based on a conceptual model we developed mentioned previously entitled Andersen's Adapted Behavioral Model of Health Care Utilization for Transgender People. See Figure 2. This model examines both individual and contextual characteristics informed by the current literature review that lead to utilization of health care among transgender people.

Recommendations

1. *Address provider lack of knowledge through online tools, resources, and electronic health records* (Enabling Resources)

Many online tools and resources provide quality, comprehensive information for health care providers on how to best meet the health care needs of transgender individuals. The University of California at San Francisco (UCSF) Center of Excellence in Transgender Health[52] and the National LGBT Health Education Center,[53] a project of the Fenway Institute in Boston, are two specific medical education programs that offer evidence-based, online training modules. Many health care clinics and facilities are overburdened with the demand of treating many patients. Utilizing online tools, therefore, is a convenient and economical resource that can offer health care providers the ability to increase their knowledge concerning transgender health care issues. These online training tools are a vital enabling resource that can facilitate transgender individuals to have a positive health care experience that will lead to greater health care utilization and overall better health outcomes.

Additionally, providers must gain knowledge about best practices when using electronic health records (EHRs) with transgender patients. Electronic health records typically only capture a patient's sex assigned at birth and omit the patient's gender identity. This lack of gender identity can be detrimental to the patient, because the provider may not know what organs the patient possesses. For example, a provider may not know that a transgender man may still have a uterus and require gynecological exams. Providers need to learn how to utilize a two-step technique with EHRs in order to capture a patient's gender identity information.[54] This process entails querying the patient's gender identity first followed by a query of the patient's sex assigned at birth. For a more detailed discussion of this procedure (which is beyond the scope of this paper), see Deutsch et al.[54]

2. *Document and disseminate previous negative experiences/anticipation of these experiences* (Enabling Resources)

As mentioned earlier, one of the biggest reasons transgender consumers are hesitant to utilize health care services is due to previous negative experiences with providers or the

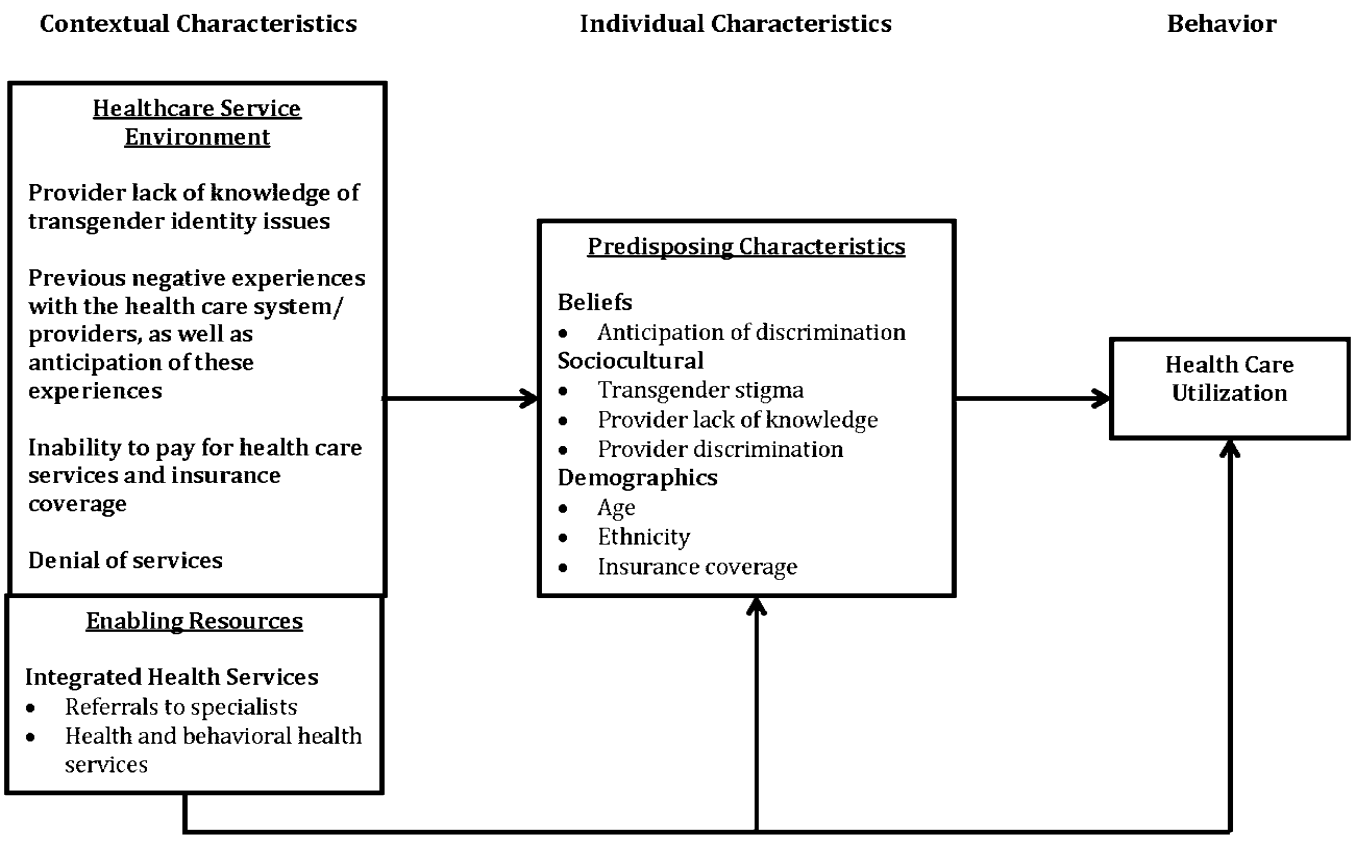

Figure 2. Adapted Behavioral Model of health care utilization for transgender people.

anticipation of having these types of experiences. Leading LGBT and transgender-specific focused organizations, such as the National Center for Transgender Equality (NCTE) and Fenway Health, could begin to create a database to document the negative experiences that transgender people face in utilizing health care. As mentioned earlier, Grant et al. documented in the largest transgender sample to date (the National Transgender Discrimination Survey) that 25% of a sample of 6,456 transgender people delayed needed medical care due to disrespect and discrimination from medical providers.[13] This survey could be used as the beginning of a national database that could help identify where transgender people are experiencing or anticipating experiencing negative interactions with health care providers. The 2015 U.S. Trans Survey (U.S.T.S.) is the follow up to the National Transgender Discrimination Survey, and it is projected to be administered every five years with the first release of data available in mid-2016.[55] These databases can serve as an enabling resource. By empowering transgender individuals to have the information necessary to make informed decisions about which health care providers to use for their care, these clients may ultimately utilize greater levels of health care.

3. *Acknowledge and address the underlying reasons for the inability to pay for health care services* (Predisposing Characteristics)

Health care affordability in the United States has long been a concern for all types of health care consumers. With the advent of the Affordable Care Act (ACA), more people in the U.S. have become insured. Transgender individuals, however, continue to experience difficulty accessing and paying for insurance since the majority of health care in the U.S. is employer-sponsored. Transgender individuals are vulnerable to employment discrimination in the U.S. due to the fact that no federal protections exist to cover transgender individuals from being fired from their jobs simply because they are transgender. In order to address the insurance gap, comprehensive employment nondiscrimination protections will need to be enacted to confront this barrier to health care. See Lerner and Robles for a more detailed discussion of transgender employment discrimination concerns.[56]

4. *Combat provider denial of services by utilizing health care advocates* (Enabling Resources)

Navigating health care concerns can be difficult for any person in the United States since health care is such a complicated system. With the advent of the Affordable Care Act, health care navigators are currently a resource offered as part of the program.[57] These navigators help people in the U.S. apply for health insurance and navigate a system that can be fraught with administrative bureaucracy and complications. While these navigators do not currently help with utilizing health care once someone has obtained insurance, their role could be expanded to that of health advocates. For example, many companies offer services to their employees to help navigate challenges associated with utilizing health care. Health Advocate is the nation's leading health care advocacy and assistance company that works with many major organizations.[58] Leading LGBT organizations could work out partnerships with companies like Health Advocate as well as the U.S. government to help facilitate challenges when providers deny transgender people services. Since companies like Health Advocate typically work with organizations that provide their employees health insurance, the lack of employment discrimination protections will still factor as a barrier to utilization. Innovative

solutions, however, to utilizing a company like Health Advocate as well as health navigators (since this workforce is already in place) could be instrumental in shifting the landscape of providers denying services to transgender individuals.

5. *Increase the current literature on health care facilitators for transgender people* (Enabling Resources)

Very few studies mentioned experiences transgender people had that increased their utilization of health care. More empirically driven studies are necessary to better understand how to provide quality, accessible health care to transgender people. The current literature review uncovered that integrating health and social services may be critical to produce better health outcomes for transgender patients. Future studies need to explore potential facilitators. Some of these facilitators may include referrals to transgender friendly providers, the presence of transgender peer educators, instrumental support for transgender people, and obtaining all necessary medical needs from one provider.

Limitations. Limitations in the present study must be considered. The search strategy may not have been robust, since the strategy only included articles made available through major literature depositories. Many unpublished or alternate forms of publications, therefore, may have been omitted. Many of the reviewed studies relied on qualitative methods as well as non-probability sampling methods, thus potentially limiting the generalizability of the findings. The present study also found that many of the quantitative studies contained low to medium methodological rigor since the studies were often based on convenience sampling.

Conclusions. Transgender individuals perceive a number of barriers to utilizing health care services in the United States. These barriers include providers' lack of knowledge concerning transgender identity issues, previous negative experiences with the health care system as well as the anticipation of these experiences, the inability to pay for health care services (often a result of a lack of insurance coverage for transgender specific procedures), and a denial of health care services. The majority of these themes were prominent in the literature reviewed in the current study. Much less information is understood about the factors that transgender people believe facilitate utilization of health care services. Some evidence exists, however, that integrating health and social services may help facilitate utilization of health care services.

Our findings suggest several strategies for creating better services as mentioned above in the recommendations utilizing Adapted Behavioral Model of health care utilization for transgender people that focuses on transgender specific health care concerns. Barriers and facilitators may fluctuate across the different stages of a transgender person's lifespan. A more extensive investigation of these facilitators and barriers as they play out at each point of utilizing health care services is critical in order to advance knowledge within the field. We encourage future studies to utilize and to build upon our Adapted Behavioral Model of health care utilization for transgender people that will exclusively focus on how to increase health care utilization among transgender people in the U.S.

Conflict of Interest Statement

The authors declare that there are no conflicts of interest.

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